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ABSTRACT

This document addresses the dilemma faced by families with an aging or disabled member and the stress associated with the role of family caregiver. Emotions experienced by family caregivers, especially when the caregiver is an adult child caring for an elderly or frail parent, are discussed and feelings of desertion, dependence, and sibling rivalry are considered. The trauma of placing a relative in a nursing home is discussed and the difficulties involved in properly timing the adult child's responsibility to make decisions for a parent, and in making wise decisions, are examined. Possible guidelines are offered to help caregivers cope with the stresses associated with the caregiver role. Suggestions are given for where families can turn for help or advice in handling their role as caregiver. (NB)

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Widening the Generational Circle:

Family Caregivers

by Bert Kruger Smith

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Editor's Note

Bert Kruger Smith was Conference Lecturer for a weeklong training series at Montreat, North Carolina, that involved working leaders of programs for older adults in congregations and communities. Throughout the week, she made five presentations before an audience of 120 lay leaders, pastors, church educators, teams developing new ministries, and those interested in improving their skills as leaders of older adults.

One of those five lectures was titled, "Oasis in the Desert—Symposium on Mental Health of the Caregiver." That message is reprinted here as *Widening the Generational Circle: Family Caregivers.*

Widening the Generational Circle:
Family Caregivers

"What shall we do with Mother?"

"Who is going to look after Dad?"

These questions surface in familes as middle-aged "children" try to solve the dilemma of caring for frail parents who may no longer be able to live alone. The questions do not find easy solutions.

For example, Frances and Tom are in the car returning from the initial process of having placed Frances' mother in a nursing home. They have done so after months of agonized attempts to find someone to care for her in her apartment 24 hours a day.

Now Frances is crying with the abandon of a little child. "How could I do this, Tom? Did you see how she looked at me when we said goodbye? I'll never be able to forgive myself."

Tom cannot comfort Frances, cannot remind her of the time Mother had set her apartment on fire. Warming some milk at midnight, she had forgotten the pan on the stove. Only because she also forgot to put the milk away and left the carton on the next burner where it had burst and extinguished the fire was a disaster averted. He cannot remind her that Mother's 3 a.m. telephone calls and bizarre behavior have made the other apartment house residents petition the manager to ask her to leave.

Tom cannot assuage Frances' sense of grief and guilt and misery concerning her mother.

. . .

Or, take Anna—a career woman who tries to do her best for her family. Her mother died five years ago, and her father, who has been living in his own apartment, seems to be deteriorating before her eyes. Grandpa and teen-age daughter, Julie, often argue with one another, and she is fearful that bringing her father into her home might set off family tensions.

Still, it looks as if Father cannot live alone much longer. How can Anna set priorities and make decisions? Does she give up her career? Will Julie leave home if Father comes into it? What about Anna's marriage? Will some existent tensions with her husband increase?

And—if she does not bring Father into the home, can she justify her actions without feeling guilty?

. . .

Let's look for a moment at Joyce. She has worked through many of the negative feelings she had about placing her mother in a nursing home a year ago. Mother seems to have made a fairly good adjustment, and Joyce and her family come out frequently and take her for rides and family outings.

Now Joyce's brother, with whom she has never related well, insists that he is coming to town to remove Mother and to take her to his home. How will Joyce sort out her feelings and be able to work out some solution which will not harm her mother?

. . .

The problem of "what to do with Mother (or Dad)" becomes an all-absorbing one for multitudes of people. In a society where more than 50 percent of the women work, where nuclear families are removed from close and caring "others," where the over-75 age group is growing faster than any other segment of our population, the dilemma of how to cope when parents grow increasingly needful is one which many people are trying to solve.

The statement that "our parents took care of their own and also looked after us; yet we are unwilling to tend to them as they have special needs" is made frequently. Although it holds some truths, it is not the entire truth of itself. The situation of an enormous population of old people has not existed before in this country, where in the early 20th century only one person in 25 was 65 or older. That number jumped to one in ten by 1970, to one in eight or nine by 1980, and it is predicted that it will be one in five by the early 21st century.

Longer years have brought with them increasing fragility and, for some, increasing mental disability. Many of the frail elderly have needs so complex that any household would be taxed to care for those persons without professional assistance.*

*Smith, Bert Kruger, Jacqueline Lelong, and Bettina Adelberg, *Aging Parents & Dilemmas of Their Children*. Hogg Foundation for Mental Health, 1981.

Coming Out Even

The family caregiver is often shredded like confetti and in about as many pieces.

Persons responsible for frail and aging parents endure dozens of emotions—good, bad, rewarding, depressing—all of these separately and in combination. The "children" share an emotion all too common for many of us—guilt and other negative feelings. Unresolved emotions simply do not disappear. Rather, like a ball pushed down under water, they continue to surface over and over and over.

Leftover emotions, like leftover food, may spoil and contaminate what is close by. Good recollections have a tendency to fade like old photographs, and soon memory captures only the present with its unpleasantries. What happens to people emotionally, when they witness their parents' disabilities?

For one, they feel vulnerable and unmasked. In a sense, their own support fence has been taken down. They are next in line.

When one looks at a parent's aging, he also has to see into the mirror of the past and in the mirror of the future. Even at forty, or fifty, or sixty, we are still our parents' children. We continue to react to the emotions that we had when we were small children.

Because residues of unresolved emotions may pollute the living waters of the present, the maintenance of positive relationships may be difficult. The older parent who has always been domineering and who refused to let a son or daughter make decisions about his living or welfare raises a dilemma for the adult child, who may see that solitary living is dangerous for the parent but who is reluctant to use force to change his residence.

On the other hand, the needful mother living with her children may use every ploy at her command to win over the grandchildren by overindulgence or conspiracy about their behavior and may even extend her emotional demands

to her children's friends and relatives. The struggle between parent and child (even when the "child" is past 50) may result in tensions in the younger family, withdrawal on the part of the older parent, and unhappiness all the way around.

Desertion

One big residue is fear of desertion. Parents—strong, able—have always been close to rescue or reassure. And now here the children are—40 or 50 or 60—and the substantial parent is frail and needy. "We have been betrayed! How does he dare grow old and leave us to fend for ourselves?" the subconscious moans. In trouble or sadness we could always depend on parental support. And now it's gone.

Dependence

Or, dependence might be carried forward in another way. Maybe one feels, "Father made me depend on him for every dime I wanted to spend. Now he's old and comes to me for tobacco money or drug items. I'll show him—I'll make him ask as he made me." (That's the subconscious talking. The conscious says, "Sure I'll look after the old man. Of course, he shouldn't have a lot of money; he's so forgetful. But I'll get him what he needs if he'll just ask me!").

Sibling Rivalry

"Helen always was Pop's favorite. She ought to take him in her home."

"I'll have Mom to dinner on Sundays. Fred lorded it over me long years about how he and

Mother loved to read poetry together after Sunday dinner."

That's the subconscious again, like a stone in your stomach.

We have all kinds of not-too-pleasant feelings.

There's FEAR that we will turn into them.

There is also ANGER—again—at our parents for growing old and helpless and dependent on us.

We have POWER needs which work both ways. We are in control on big and little decisions. (And they are in control in subtle but realistic ways.)

GUILT—How can I, strong and functioning, be hostile to this seemingly helpless parent?

SORROW, SENSE OF FAILURE. RESENTMENT. HELPLESSNESS. SHAME. And others

Sometimes the strain becomes too much. Sometimes the yo-yo existence of going back and forth from one generation and one task to another grows too heavy. The yo-yo won't bounce up anymore, and something breaks. In recent years that break has often taken some form of abuse of the elderly—abuse which is physical, psychological, or financial. Oftentimes the abuse is carried out not by monsters who want to put an older person out of the way but by people who are so stressed in life that they lose their own controls.

Sometimes the strain evolves into placement in nursing homes.

Our society is quick to blame families for putting parents in a nursing home. And families are just as quick to feel guilt over doing so.

"They just wanted to get their mother out of the way," people may say, or, "He'll put his father there and never visit him."

The truth is that most institutionalized elderly have multiple chronic disabilities which may be physical or mental. They need constant supervi-

sion and extensive help in personal care and activities of daily living.

Prior to institutionalization, most families have endured severe personal, social, and economic stress in attempting to avoid admission. Usually the decision to institutionalize is made painfully as a last, not the first, resort. The non-institutionalized spouse, if there is one, usually is not strong enough to continue the level of care demanded by the sick mate's needs. The adult children often are approaching the aging phase of life. They are undergoing stresses and often are subjected to competing demands from ill spouses or their own children.

No matter what the rationale or justification, placing a loved one in a nursing home is traumatic for all parties.

For the younger generation, such placement may mean having to look squarely at one's own aging—often an unpleasant option. For a spouse, it spells dramatic and usually painful change.

For the older person such placement may be summed up in one word, loss—loss of possessions and feelings which, until that time, have been uniquely one's own.

Any movement so fraught with deep emotion is bound to have a profound impact on both generations.

Timing Is Difficult

When should one step into a parent's life and make decisions? The question itself should be rephrased because, if one is wise, he works with his parents in the decision-making process early on and continues so long as the parent is able to help in that area.

A person needs to try to intervene at just the right time. Like Goldilocks, who found one bowl of bear's porridge too hot, another too cold, and the third just right, we sometimes move too quickly with decision-making. We may misjudge overmedication, sorrow, depression, certain physical ailments for senility and rush to change our parent's lifestyle from semi-independent living to institution.

Or, conversely, we may be too late. We wait and wait and wait long after physicians and friends and neighbors have said that the time has come—indeed, the time has passed, for our parents to live alone. Only occasionally are we just right in our timing. We have to sort out whether we are concerned about their needs or ours—their self-concepts or our fear of being judged by our peers.

Despite these negative portrayals, we know that most families mean well. They want to do what is "right," if they only knew what "right" is!

Interlacing all of these negative feelings, coloring the waters of our displeasure, are our tender memories and our loving concerns for both generations. Even while we feel resentment at the never-ending needs we must meet, we carry within us memories of the years when we took from parents' strength, were nourished by their love, fed by their compassion—when our pain was lessened by their caring and our joy increased by their sharing.

Sometimes we have to remind ourselves to recall that the needy parent was also the strong one at another time and in another season. It is important not only that we remember the competencies of that mother or father but that we share with them our memories of their abilities.

Even when the parent's condition has deteriorated and the adult "child" despairs of "reaching" the parent in any meaningful fash-

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ion, there still remains a basic and primitive residue of caring which can help both generations.

What can I talk about with a parent who may not reply or who may not recognize who I am? That question is asked often by people who pay visits to parents whose memories have diminished and whose responses are shallow.

Blessedly, touch still remains. And touch may speak more loudly than words. Particularly in the old, who often seem unappealing and untouchable, a hug, a touching of hands, a kiss may be renewing and rewarding. It isn't even necessary always to talk. Simply sitting together may be therapeutic. And if there is a common task to be shared—the folding of socks, shelling of peas, or putting away dishes—such working together can be of value to both people.

Sage Decisions Are Difficult to Make

The adult children have to remember to be good to themselves to the extent possible. Energies are not unlimited; neither are emotional strengths. It is important to find that amount of vitality which can be garnered for the various generations and to marshal efforts based on that knowledge—remembering always to leave some time for self.

The middle generation has both the best and the worst of it. It holds the key positions, authority, earning capacity, control of its own destiny and to a large degree the destinies of teenagers and the old. However, it also has the responsibility for supporting all three or perhaps four generations emotionally and for somehow

resolving the intergenerational conflicts in such a way as to hold the society together.

Social agencies are just now beginning to understand the really desperate needs these pivotal people have in coping with problems of older and younger generations plus their own emotional feelings of guilt and resentment. Sometimes generations impinge on one another. Sometimes an aging parent is brought into a home already altered by the return of a grown daughter and her small child. Life at home can become difficult for all.

The middle generation is the one that suffers most. Often these persons are near retirement age and in need of special respite for themselves. Or, sometimes such a move is therapeutic, adding a new caring dimension to all ages.

The middle-aged sons and daughters are the ones who have to decide what is the best method of caring for a parent with special needs while maintaining a household with mentally healthy people living together.

Since no one can move back in time and change what has already happened, the only options left are to practice basic mental health principles for oneself and on behalf of the other person. Perhaps one important first step is to recognize the emotions for what they are. If childhood anger or feeling of injustice or rivalry with a sibling can be recognized, if the mummy wrappings of long-ago emotions can be taken off, then a person is ready to differentiate what is reality now and what is overlay from unresolved sensations of earlier years.

Such revelation may be difficult to obtain, and sometimes it is desirable that an outside person be consulted to help with the sorting process and to suggest guidelines for behavior. The psychological hazards are avoidable for the most part if

people can recognize them and can deal with feelings on an honest and forthright basis.

One of the best techniques is to get some physical and psychological distance between the persons most tied together in emotional problems. Both of them, in each generation, need to move away from one another instead of clinging closer and tightening the raveling rope which binds them.

One important item we must remember is that we are being watched!

All of the time that we have been looking at our parents growing older and have been making all these decisions about what we are going to do with and for and because of them, our children have been watching us. They have taken their cues from us just as we learned from the generation before us. They have seen how the powerful treat the powerless; they have witnessed our reactions and emotions.

The story is told that in one of the ancient villages where the custom was to carry the old and infirm up to the mountaintop to die, a son was going up the mountainside with his father on his back. He felt a tear on his neck and said, angrily, "Father, why are you crying? You know that I have to do this. It is the custom." The father, in a weak voice replied, "Son, you don't understand. I was not crying for myself. I was weeping for the day when your son will carry you up the mountainside to die."

Possible Guidelines

Perhaps the first thing we need to do is to increase our own regard and feeling toward the old and then to see ourselves in some reality and

to come to terms with our own mortality and our own views of aging and of death. The task is not easy, nor is it accomplished overnight. Yet, once we unmask and recognize our emotions and deal with them, we can respond positively to others, our parents included.

We need to see ourselves and to examine our own emotions with candor and with honesty, a most difficult process. We need to educate our young to be better able than we to meet these changing roles.

Our feelings are like dark spots which keep surfacing on the clean cloth of our lives. We cannot cover or "bleach" them.

Once we learn to know ourselves realistically, we can reach out to both generations in loving fashion. There is much we cannot change. And in those instances we need to recognize and not battle the unchangeable.

At times all that we can change is our own attitude (and thus our own behavior).

No one can really make us angry or hostile or unhappy.

We have responsibility for our own lives.

Finally

Can the family caregivers be aided in their difficult task to do justly to all generations?

With the help of support systems offered by the churches and other community groups they can be aided to shore up their own strengths and to balance in some measure the multiple demands which are made of them.

One woman tells the experience of being a small child with a tubercular brother. In those days a person with tuberculosis was isolated, and his clothes and eating utensils were kept separate.

It so happened that the child's parents had to leave for a brief period of time and admonished her to look after the brother. Shortly thereafter he called her, and she stood in the doorway while he asked for a drink of water. She went into the kitchen but could not find a glass which was set aside for him. Finally she located a cracked fruit jar and put his water into it.

She has said, "Although I am now a middle-aged woman, I shall never forget the look on his face when he saw how I had delivered his drink of water, in a container which was defective and unusable."

There is a lesson for us all in that story. We have to be sure that we deliver services to our frail elderly in vessels which are whole. We need to let them know that they are valued as important people in our society.

Where to find help . . .

Families seeking advice or direction might contact branches of state and national organizations as well as local agencies. Some of the headings under which these may be listed in directories are:

Aging services
Human services
Mental health associations
Senior citizens service organizations
Social service organizations